

Research Studies

Scientists want to learn more about the diseases that cause memory loss and dementia. Many research studies are being done. The goals of these studies may be to:

- Help us understand more about how these diseases change the brain
- Help us understand what triggers these changes
- Test treatments that may prevent or delay these changes

Research studies work with volunteers who want to take part in the study. Some studies include people with a certain disease or who have certain symptoms. Others include people who do not have cognitive changes.

Taking part in a research study is one way you can make a difference. You can help build scientific understanding and help researchers find new prevention and treatment methods.

Clinical Trials

One type of study is called a *clinical trial*. The goal of this kind of study is to see if a treatment works and if it is safe. In a clinical trial:

- Volunteers are assigned 1 or more treatments.
- Scientists monitor these people to see how the treatments affect them.
- Most volunteers also continue any treatments they are already using.

Control Groups

Some volunteers in a clinical trial may be in the *control group*. This means they do **not** receive the trial treatment for at least the first part of the study. Instead, they may receive a *placebo* (a substance that does not have a medicinal effect), or no added treatment at all.

Scientists monitor people in the control group. They compare their health to the health of the people who receive the treatment.

If You Want to Take Part

If you want to take part in a research study, please keep in mind:

- Research studies are separate from the care you receive from your healthcare providers.
- Taking part in research studies might **not** improve your health.
- Before you enroll, staff who are running the study will explain the study's goals, what it involves, and possible risks and benefits. You will receive a written copy of this information.
- You can choose to withdraw from a research study at any time.

Here are some places to learn more about research studies:

Memory and Brain Wellness Center Research Registry

If you are a patient at UW Medicine Memory and Brain Wellness Center (MBWC), you can enroll in our Research Registry. This is a list of people who are interested in taking part in research studies. If you are interested, talk with your MBWC doctor or nurse practitioner.

It is your choice whether or not to enroll. Your choice will not affect the care you receive at MBWC.

Other Local Resources

- UW Alzheimer's Disease Research Center:
www.depts.washington.edu/adrc
- Pacific Northwest Udall Center for Parkinson disease research and brain donation: *www.panuc.org*
- Memory and Brain Wellness Center clinical trials list:
www.depts.washington.edu/mbwc/research/clinical-trials

National Resources

- Database of research studies maintained by the U.S. National Institutes of Health: *www.clinicaltrials.gov*
- Research study matching service offered by the Alzheimer's Association: *www.alz.org/trialmatch*
- List of research studies for people diagnosed with a form of FTD, offered by the Association for Frontotemporal Degeneration: *www.theaftd.org*